

Letters to the Editor

Objectives and Activities of the Genetic Alliance

As founding director and executive director of the Genetic Alliance, we read with interest the recent article by Dr Adrienne Asch.¹ The reader gained an in-depth understanding of the social and ethical complexities underlying reproductive decision making based on prenatal genetic test results. Selective pregnancy termination raises questions that are profound for individuals and families living with disabilities, for parents confronting decisions about an expected child, and for voluntary organizations, like the Alliance, that provide resources, support, and referrals to parents and professionals.

Since 1986, the Alliance has grown to become a nationally recognized coalition of consumers and professionals working together to enhance the lives of everyone impacted by genetic conditions through public and provider education, public policy, and support group technical assistance. Because of daily calls to our Helpline from parents and affected individuals in the midst of making decisions about and coming to terms with genetic test results, the Alliance is very familiar with the nuances and complexities of these issues in the lives of real people. These issues are ones we know personally as well as professionally through our experiences within our own families and our commitment to the Alliance.

Because of the commonality of our concerns, we were dismayed and disappointed by the author's misperceptions about Alliance mission objectives and activities. From its founding, the Alliance has been involved in research policy discussions, particularly regarding informed consent, and human protection and privacy issues. However, the far greater portion of our energies is devoted to providing the support, resources, and referrals to information systems that empower parents, individuals, families, and significant others to gain access to quality, family-centered, culturally competent resources and services, make informed decisions, and

live lives to the fullest extent possible. The Alliance has *always* been involved with and supported disabilities issues and will be expanding these commitments, along with other activities, in the future. We suggest that readers, as well as Dr Asch, look to the Alliance Web site at www.geneticalliance.org for a current and comprehensive perspective on Alliance activities and mission objectives.

The specter of rapid commercial availability of genetic tests provides a compelling reason for consumer organizations to collaborate and coordinate efforts to ensure that benefit, not harm, results from these new technologies. This is, and has always been, a primary Alliance concern.

We believe the Alliance has worked hard to become a sensitive and effective voice for all who are affected by genetic conditions. We invite you and your readers to watch our progress in developing into a major force for consumers and their families, not only in the genetics community, but also in society at large. □

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References

1. Asch A. Prenatal diagnosis and selective abortion: a challenge to practice and policy. *Am J Public Health*. 1999;89:1649–1657.

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